

MASS. DCI.1:996

* UMASS/AMHERST *



312066 0362 9054 8

COMMONWEALTH OF MASSACHUSETTS

DEVELOPMENTAL DISABILITIES COUNCIL

DOCUMENTS COLLECTION
MASSACHUSETTS
UNIVERSITY OF MASSACHUSETTS
LIBRARY, 100 HILLS
100 HILLS, 01003

RECEIVED

AUG 28 1997

DOCUMENTS
COLLECTION

Annual Report

FEDERAL
FISCAL
YEAR

1996

October 1, 1995 - September 30, 1996

Massachusetts Developmental Disabilities Council
174 Portland Street - Fifth Floor
Boston, Massachusetts 02114

HOWARD J. WAYNE
CHAIRPERSON

(617) 727-6374 (Voice) (617) 727-1885 (TTY)

WILLIAM F. WELD
GOVERNOR

ANNUAL PROGRAM PERFORMANCE REPORT
FEDERAL FISCAL YEAR 1996

TABLE OF CONTENTS

Section I: Identification Data	3
Section II: Reporting Year (FFY 1996)	4 -17
A. Mass. DD Council Objectives:	4 -13
1. Family and Individual Supports	4 -7
2. Health Care	7 -10
3. Employment	10-12
4. Multi-cultural Infusion	12-13
B. Innovative Council Activities	13
C. Major Council Accomplishments	13-17
Section III: DD Program Expenditures	18-19
Section IV: State Actions on ICFs/MR	20
Section V: The State Picture	21-36
A. Overall Trends	21-26
B. Un-and Under-served Groups	26-29
C. Resource and Funding Priorities	29-30
D. Policy Reform	30-32
E. Advocacy	32-35
F. Other Actions	35-36
Appendix A: Resources Leveraged	37
Appendix B: Dissemination Plan	38
Appendix C: List of Members/Staff	39-40

I. IDENTIFICATION DATA

1. State:

MASSACHUSETTS

2. Federal Fiscal Year Reporting:

Federal Fiscal Year 1996
October 1, 1995 - September 30, 1996

3. Name of Council:

MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL

174 Portland Street, Fifth Floor
Boston, Massachusetts 02114
(617) 727-6374
(617) 727-1885 (TTY)
FAX (617) 727-1174

4. Designated State Agency:

ADMINISTERING AGENCY for DEVELOPMENTAL DISABILITIES

174 Portland Street, Fifth Floor
Boston, Massachusetts 02114
(617) 727-4178
(617) 727-1885 (TTY)
FAX (617) 727-1174

5. Does the Designated Agency provide direct services: **No**

6. Name of Preparer:

Deirdre A. Whelan, Esq., Legal Counsel
Massachusetts Developmental Disabilities Council
Telephone Number:(617) 727-6374, x. 102

II-A. REPORTING YEAR OBJECTIVES

✓ (Indicates Innovative Activities Requested Under Section II-B)

OBJECTIVE #1

1. **Name and description of objective: System Coordination/Community Education (Individual and Family Supports)** Increase the Commonwealth's commitment to culturally appropriate family and individual supports; build a knowledge base about respite care (an area of unmet need in family and individual supports); increase community awareness of disability issues; maximize impact of Council-funded Grants/Projects.
2. **Goal:** Increase family and individual support services for persons with developmental disabilities of all ages in Massachusetts.
3. **Extent to which objective has been met:** This objective is considered ongoing, at least through FFY 1997.
4. **Expenditures for this objective (through 9/30/96):**
Federal \$ 87,557 State \$ 13,708 Total \$ 101,265
5. **Priority area activities under this objective:** System Coordination and Community Education
6. **Activities pursued for meeting the objective:**
 - a. Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
 - b. Study or analysis
 - c. Gathering information
 - d. Demonstration project
 - e. Outreach activity
 - f. Development of model policies and procedures
 - g. Presentation (formal or informal) to policy makers
 - h. Training for access to or for provision of service
 - i. Other similar activity to prevent developmental disabilities or to increase independence, productivity, and integration
 - j. State Plan development
 - k. Activity addressing the implementation of 1990 Report findings. If activity is also a priority area, then please check both.
 - l. Coordinating activity, other than above.
 - m. Advocacy activity other than above (commenting on other State plans, State ICF/MR actions, unserved, underserved, other).
7. **Summarize the activities for this objective.** The Council continued to support Massachusetts Families Organizing for Change (MFOC), a grassroots organization of family members of people with disabilities. The MDCC provided fourth year funding to support MFOC to incorporate, obtain training in diversity/multicultural outreach, and to support regional efforts. Members of MFOC focused their efforts on educating State senators about the Individual and Family Supports Bill, and participated in the MDCC and ARC Mass' legislative reception at the State House. MFOC provided family leadership training sessions (and an advanced leadership series for over forty people); and supported the efforts of members at the regional level. MFOC has obtained a

one-time innovative grant from DMR, and in the Boston region, a telecommunication project was started. MDDC staff continued to attend monthly Steering Committee meetings of MFOC in Boston.

The state budget for 1997 mandated the continuation of the three family support pilots (first funded by the state in 1996). These pilots were to be supported by three state agencies (Department of Mental Retardation(DMR), Department of Public Health (DPH), and Department of Education (DOE). A Memorandum of Understanding was signed in October 1996 between DMR and MFOC, and MFOC members were actively involved in the family support pilots. DMR has provided most of the funding, and DPH a small amount. The MDDC agreed to fund an evaluation component to measure the effectiveness of the pilot projects.

The Council continued to support Citizen (Family and Individual) Support Legislation as its priority bill on its legislative platform, and continued to advocate for increased state funding for family and individual supports. MDDC members and staff provided testimony at legislative hearings and communicated with legislators and committee members throughout the year to effect passage of the bill. The MDDC Legislative Advocacy Training grantee provided training to MFOC on how to develop a legislative strategy. Due to the efforts of the new Chair of the Senate Ways and Means Committee, the Citizens Support bill passed through the Senate for the first time, during the last week of the legislative session this summer. Unfortunately there was not enough time to proceed with the House.

The Council held its eighteenth annual Legislative Reception in conjunction with Arc Massachusetts. Over sixty advocacy organizations cosponsored this event, whose theme was "Building a Community for Everyone: Reaffirming Government's Responsibility for Persons with Disabilities." Over two hundred and fifty consumers, family members, and advocates attended the Reception. The program included consumer speakers and "legislator of the year" award presentations. Speakers gave special recognition to over seventy-five legislators and aides who were present. The Council's legislative advocacy grantee provided attendees with guided visits to their legislators after the program.

The Council's Family Support/Multi-Cultural Project, targeting families in Hispanic and African-American communities in the western part of the state, completed the final year of grant activities. The grantee focused on educating families about family support services, increasing access to services and developing linkages to family support movement. By the end of April 1996, the Project had served over 35 family members in support groups and provided access to several trainings throughout the state.

The following new grants were awarded under the Supports priority area in 1996:

1. Horace Mann Educational Associates—"Families, Information, Referral, Support and Training" (FIRST)—Provides outreach to approximately 25-40 families in Worcester and recruits and trains 3-5 high school students from the Asian and Latino communities to assist in providing outreach and interpreting. An outreach coordinator, assisted by the students, will identify priority needs and develop a Family Support Plan written in the families' primary language. The project will create brochures and informational pamphlets for distribution in Worcester's multicultural communities.
2. Arc Massachusetts—"Facing the Waiting List Challenge"—Enhances the capacity of the "Family to Family Chain" to reach out to individuals with developmental disabilities and families from multi-cultural backgrounds who are on the waiting list for community based services. The waiting list includes people in the Turning 22 population, those whose primary caregivers are over age 60, and those seeking assistance for residential services. This coalition links families on the waiting list with other families in the targeted communities to develop creative and alternative solutions to the services they are lacking.
3. Dept. of Mental Retardation—Cape Cod Office—"Outreach to Native Americans on Cape Cod"—

Increases access to Native American Tribal Councils to family support services on Cape Cod and the Islands; establishes two work groups with the Gay Head Tribal Council and the Mashpee Tribal Council to develop a specific work plan around the needs and characteristics of the tribe and its members.

4. Martha's Vineyard Community Services—"Wampanoag Tribe of Gay Head Family Support Outreach Project"—Provides outreach to tribal families who are in need of family support services; connects tribal families to family support services within the island community; identifies and develops a protocol for a community organizer or person from the tribal human services program to serve as a contact/resource person to assist families and individuals with developmental disabilities; develops a network of tribal families who have members with a developmental disability; develops a lending library for families; and provides opportunities for families to become more familiar with the family support movement.

The Council provided a grant to the Disabled Persons Protection Commission (DPPC) to develop strategies for abuse prevention through education. The DPPC oversees and/or investigates abuse allegations, and refers cases to state agencies as appropriate. First year activities included providing support to the Abuse Prevention Task Force; collecting and cataloguing information and resources; convening a broad base of stakeholders and conducting trainings, materials development and outreach activities. As a result of the project, the DPPC has integrated and enlarged its agency-wide commitment to prevention, especially through training and outreach, with added emphasis on data analysis. MDDC Staff continue to attend meetings of the Disabled Persons' Protection Commission's (DPPC) Task Force on Disability Abuse Prevention.

The Council continued to advocate for housing for people with disabilities. The Mixed Populations Housing Bill, which passed last year, included funds for service coordinators, the Housing Registry, and rent subsidies. Staff provided information on housing issues, especially for children, to staff of the Governor's Commission on Mental Retardation and other members of the public. In addition, the Council provided funds to Citizens Housing and Planning Association (for "Home of Your Own" Program Awareness) to produce outreach materials about the Home of Your Own Program and to cosponsor a conference to provide information to people with disabilities on how they can own their own homes or create alternative housing solutions.

The Council addressed a number of additional issues with the Post Audit and Oversight Committee of the State Senate, including foster care and the importance of supports for families. Comments were also provided to the Department of Mental Retardation Children's services (intensive case management and educational advocacy services); and the Department of Social Services (emphasizing the importance of supports to enable families with members with disabilities to maintain themselves in the community). Continued advocacy around children's issues included staff participation on the Early Intervention Inter-agency Coordinating Council, MDDC support of Children and Youth Advocacy Day in May 1996; and communicating developments related to IDEA to the disability community. Staff attended statewide coalition meetings, and the Council supported PCA legislation and related state budget amendments.

✓ The Supports Committee identified revising the grants process as one of its FFY 1996 objectives and the changes have benefited all priority areas under the State Plan. In FFY 1996, the AADD reformed its grants process by streamlining the application process, using council members as grant reviewers, and ensuring that grants will have an ongoing post-project impact.

✓ This summer's grants review process was the first time where MDDC members, staff and Committee members took an active role in reviewing grant applications. It was also the first grant cycle where a two-tiered review process was used. Grant reviewers met in June to evaluate a total of 92 preliminary applications and selected applicants for final consideration. In August the reviewers evaluated the final applications and submitted their recommendations for funding.

In the past, Council members conceptualized grant projects and objectives, but once the grant was put out for bid, the members no longer participated in the process. An independent grant review committee would evaluate proposals. Subsequently, there were times when grants were awarded did not completely address the intent of the main objectives.

The original policy excluding Council members from the grants award process was implemented to comply with the Commonwealth's conflict of interest (COI) law. Among other things, the regulations prohibit participation in awarding contracts when there is a real or perceived conflict of interest. The DD Program separated the development of grant proposals from the awards process to avoid incurring the COI law. This year, after a legal review and confirmation from State's Ethics Commission attorneys, the Council structured its grants process so a Council member who had no financial interest could participate in the review and award of grants. As a result, committee representatives who had the most expertise in what the goals and objectives of each priority area selected the applications for funding.

✓ Another innovation that took place with the grants process was a streamlined grants application. Rather than issuing detailed RFPs and requesting full proposals, an abbreviated set of instructions was sent out to the agency's mailing list of over 2,000 contacts. Organizations were advised to submit a brief project concept paper as a preliminary application. The results were encouraging: the AADD received the most responses ever, and many were from first time applicants. Applicants whose project ideas best reflected the council's goals were invited to submit full proposals. They were advised that priority would be given to proposals that included ongoing post-project impacts. In some instances, applicants with similar goals were asked to collaborate on each other's projects. Although the grants have just recently started, the results to date are very promising.

Beginning SFY 1997 (July 1), the Commonwealth initiated its "procurement reform". The new regulations impact the grants awarding process by requiring a multi-page boilerplate application. It is still unclear how these new regulations will impact the grants process. On a positive note, the AADD now has the capacity to post its Requests for Responses (RFRs) on the Internet. Organizations can download the application instructions and forms, giving them more time to prepare their proposals and decreasing DD staff distribution time. Finally, the AADD selected a pool of independent grants evaluators who will conduct site visits and report the results directly to the AADD and MDDC.

OBJECTIVE #2

- 1. Name and description of objective: Health Care (State Option)** Promote health care models that benefit persons with disabilities and communicate the Council's positions to policymakers; incorporate into Council health policy special concerns of multi-cultural communities, children with special health care needs, low income and low-incidence disability populations, and other underserved populations, and monitor the delivery of services to these populations.
- 2. Goal:** All persons in Massachusetts will have a right to affordable and high quality health care including all services and supports to meet their needs.
- 3. Extent to which objective has been met:** This objective is considered ongoing through FFY 1997.
- 4. Expenditures for this objective (through 9/30/96:**
Federal \$ 78,600 State \$ 13,708 Total \$ 92,308
- 5. Priority area activities under this objective:** Health

6. Activities pursued for meeting the objective:

- a. Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
- b. Study or analysis
- c. Gathering information
- ☐ d. Demonstration project
- e. Outreach activity
- f. Development of model policies and procedures
- g. Presentation (formal or informal) to policy makers
- h. Training for access to or for provision of service
- ☐ i. Other similar activity to prevent developmental disabilities or to increase independence, productivity, and integration
- ☐ j. State Plan development
- ☐ k. Activity addressing the implementation of 1990 Report findings. If activity is also priority area, then please check both.
- ☐ l. Coordinating activity, other than above.
- m. Advocacy activity other than above (commenting on other State plans, State ICF/MR actions, unserved, underserved, other).

7. Summarize the activities for this objective.

✓ The 1996 Health Care Forum, titled "Health Care for People With Disabilities: The Challenge to Massachusetts" took place on March 1, 1996. A subcommittee of six members of the Health Committee met with the grantee for the forum to discuss the content, identify speakers, and develop the format. The goal was to identify the major health issues facing people with disabilities. Some major issues identified include: (1) a disproportionate amount of money and resources are going to hospital care; (2) the devolvement of Medicaid Policy to the state level; and (3) the movement toward a reduction in entitlements under Medicaid.

Approximately 120 people attended the event: participants included a Massachusetts state legislator, public and private sector health policy makers, health care providers, persons with disabilities and representatives of other advocacy groups and organizations concerned with the health issues of people with developmental disabilities.

After a keynote address by a representative of a managed care provider for people with disabilities, there were two panels: one discussed Health Care From the Federal Perspective, and the second From a State Perspective.

Two afternoon workshops addressed Access to Community Services and Managed Care. Four major policy areas were identified: designing managed care to meet the needs of people with disabilities; consolidation of government services at both the State and Federal levels; the need to integrate coordination and support of services, such as personal assistance services, transportation, education, employment, and housing; and expansion of Medicaid. As a result of the forum, the Health Committee has been working to develop a Policy statement on health during the spring/fall of 1996.

Between April and November 1995, the Council sponsored a group facilitation process for consumers, advocates, state agency representatives, and parents to develop recommendations to improve the Commonwealth's Personal Care Assistance (PCA) programs. Facilitators were hired to ensure that the final report represented a consensus of opinion among the Workgroup participants which included PCA providers, consumers, state agency representatives, and advocates. The Workgroup met at regular intervals to discuss the strengths and weaknesses of the existing Massachusetts PCA programs, and to identify goals, funding options, and solutions to problems facing the PCA programs.

The Final Report was released in February 1996. Consensus recommendations include: to establish a PCA

advisory committee, comprised of consumers, agency representatives, providers, and advocates; to advise the state Executive Office of Health and Human Services (EOHHS) on the steps needed to implement the recommendations of the workgroup; to define the PCA as an employee; and to establish a PCA pay rate that includes compensation for employment insurances (including Social Security Benefits (FICA) and Worker's Compensation Insurance); to ensure that consumer control remains the hallmark of PCA services; to ensure that PCA services are accessible to all who need them; and to examine current funding sources in order to maximize the accessibility of PCA services to persons with disabilities.

A sub-committee of the PCA Workgroup also met to discuss PCA tax and wage issues. Its conclusions and recommendations include: that a PCA, consistent with IRS employment standards, is an employee, not an independent contractor or consultant, and is entitled to employee benefits; that it is unclear whether the state, vendor, or consumer should be designated as the employer; that the issue of who is the employer must be clearly defined and uniformly implemented in Massachusetts; that the state implement a Personal Care Assistance program that incorporates Worker's Compensation, Unemployment Insurance, and consistent administrative guidelines, and that an increase in the PCA hourly rate be implemented.

In addition, Human Services Research Institute (HSRI) produced a report on PCA policy and program costs. The Report identifies the number of persons who qualify for, but currently do not receive, PCA services in the state (including children with disabilities living at home with their families, and individuals living in institutional setting who would otherwise qualify for PCA services in their own homes). During the summer of 1996, the Health Committee corresponded with the Secretary of EOHHS expressing concern that the Division of Medical Assistance had not yet involved users of the service in discussions. Staff attended meetings of a statewide coalition of providers of PCA services and advocates throughout the year.

The Council funded the Boston University School of Medicine/Fetal Alcohol Department through a small grant to sponsor a conference on Fetal Alcohol Syndrome (FAS), to educate parents, and to provide an opportunity for parents to network. FAS and Fetal Alcohol Effects (FAE) are developmental disorders characterized by facial abnormalities, growth changes, and central nervous system disorders; although first identified twenty years ago, they remain poorly understood by many in the school, health care, and social communities. The Conference, which took place in November 1995, was co-sponsored by the March of Dimes and was attended by 22 family members and several professionals. It included presentations on the basics of FAS and fetal alcohol effects (FAE), a parent presentation on some of the successes in her son's life; time for questions and answers, sharing resources and ideas, and providing support. The Project compiled a list of over 50 local and national resources on FAS which was provided to family members at the Conference. The March of Dimes has agreed to facilitate continued meetings among the family members.

The following new grants were awarded under the Health priority area in 1996, with an emphasis on educating people about managed care issues:

1. Disability Law Center—"Health Law Advocacy Project"—to provide for the preparation of written materials on managed health care access issues, to conduct four trainings for consumers, advocates, and providers, as well as providing follow-up technical assistance (separate funding will be sought for this phase) on the affect managed care is having on persons with developmental disabilities. DLC will disseminate the results of its research in a pamphlet entitled "Know Your Rights," as well as training providers in managed health care issues.
2. Horace Mann Educational Associates—"Health Care Awareness Project"—to support the collaboration of two groups of service personnel for the purpose of improving the quality of health care for people with developmental disabilities. HMEA project staff will join forces with health care professionals to identify and eliminate barriers to quality health care. HMEA will amend the existing Emergency Room Support Project

materials (from a prior grant) to include a module on meeting the needs of people with physical disabilities. HMEA will provide training sessions for HMO, managed care staff, and health care professionals who practice in community health centers and outpatient clinics as well as developing training materials targeted to these providers.

3. Shriver Center "Accessing Community-Based Health Care"—to conduct three seminars aimed to educate people with developmental disabilities, families, caregivers, policymakers, and advocates about the managed care system, and to provide advocacy training on how to impact the managed care system. The information from the educational events will be compiled and organized and will be available on computer disc and in booklet format that will be published in at least two languages. The seminars will be audio recorded, and available on the Internet as well.

The Health Committee monitored federal and state developments in Medicare and Medicaid, advocated for legislation for health care reform (An Act to Improve Health Care Access, known as the Health Care Access bill) and for the PCA budget amendment. Council staff attended meetings of the Health Care for All Coalition to monitor progress of the Access bill and to plan public education. Staff also attended an advocacy day for the Health Care Access bill at the State House.

While developing 1997 state plan objectives during the spring of 1996, a Health Committee member raised the issue of accommodations for people with developmental disabilities accessing hospital emergency rooms. The Health Committee corresponded with the Commissioner of the Department of Public Health about emergency room treatment of people with disabilities. The Executive Director and the Health Committee Chair met with representatives of the Department of Public Health who indicated interest in addressing this issue. The Council has formed a team, comprised of representatives of DPH, Mass. Nurse's Association, Horace Mann Educational Associates, and others to cosponsor a training in this area in the fall of 1997.

OBJECTIVE #3

1. **Name and description of objective: Employment** Promote supported employment as an option within Massachusetts state government; advocate for the conversion of Sheltered Services; promote the involvement of private sector employers in advocacy efforts with persons with disabilities; promote awareness and implementation of the Americans with Disabilities Act (ADA); promote the inclusion of students with disabilities in the Massachusetts' school to work Transition Initiative; and engage in Multicultural and affirmative action activities.
2. **Goal:** Create a favorable employment/hiring climate for individuals with developmental disabilities in Massachusetts.
3. **Extent to which objective has been met:** This objective is multi-year and on-going through Fiscal Year 1997.
4. **Expenditures for this objective (through 9/30/96):**
Federal \$ 94,550 State \$ 13,709 Total \$ 108,259
5. **Priority area activities under this objective:** Employment
6. **Activities pursued for meeting the objective:**
■ a. Activity to increase capacities and resources of entities for improved service delivery to persons with

developmental disabilities

- ☒ b. Study or analysis
- ☒ c. Gathering information
- ☒ d. Demonstration project
- ☒ e. Outreach activity
- ☒ f. Development of model policies and procedures
- ☐ g. Presentation (formal or informal) to policy makers
- ☒ h. Training for access to or for provision of service
- ☒ i. Other similar activity to prevent developmental disabilities or to increase independence, productivity, and integration
- ☐ j. State Plan development
- ☒ k. Activity addressing the implementation of 1990 Report findings. If activity is also priority area, then please check both.
- ☐ l. Coordinating activity, other than above.
- ☐ m. Advocacy activity other than above (commenting on other State plans, State ICF/MR actions, unserved, underserved, other).

7. Summarize the activities for this objective.

The Consumer Education Project funded through a grant from the Employment Committee of the DD Council to Massachusetts Rehabilitation Commission's Office of Employment Services has completed its first program year of operation. The project advocates for the conversion of segregated employment slots into integrated employment opportunities for people with disabilities and educating consumers with disabilities regarding vocational rehabilitation and employment choices. The staff identified existing statewide community rehabilitation programs (CRP's) through Mass Resources Databases at New England Index, and updated the database in order to educate consumers on how to access those services and to exercise their options. Thirty-three CRP's statewide agreed to host consumer education forums for consumers and parents, and thirteen have been held to date.

✓ The DD Council awarded funds to the Governor's Commission for Employment of People with Disabilities (GPCED) to develop educational, training and marketing materials for dissemination to small business employers which address their issues and concerns about employing people with disabilities. Through this interagency collaborative effort of the DD Council and GPCED, a consultant has been hired and a project planning committee of employment training personnel, community rehabilitation providers, representatives from disability agencies and some private small business owners have developed statewide focus groups. In addition to developing informational materials about employment of people with disabilities with the assistance of the small business community and user friendly methods of distribution to small businesses, the long term outcome is the hiring of individuals with disabilities by small businesses. The first focus group was held October 21, 1996 and three additional focus groups are planned at various locations throughout the state.

✓ The MDDC also awarded funds for the Department of Personnel Administration (DPA) Pilot Project. The focus of this project is to develop a "level playing field" for the hiring of qualified individuals with disabilities into existing competitive state agency positions. This project originated as an outcome of DD Council Staff and Members being participation on the Americans with Disabilities Act (ADA) Task Force. Representatives of state employment related/disability agencies, in cooperation with the Department of Personnel Administration, reviewed the personnel laws, regulations, rules and standard practices in relationship to the ADA and Sec. 504 Compliance. The project was delayed due to proposed restructuring of state government, possible changes in state employment needs and re-shuffling of key state agency decision-makers.

Through the ADA Taskforce, agreement to initiate the project was received from the Department of Personnel and Administration. A Training Seminar for Human Resource Personnel within Massachusetts State Government has been planned as part of a marketing plan to attract voluntary participation by state agencies, and a Request For Response has been issued to select an independent evaluator. The Council is funding the private independent evaluator to assess the appropriateness of the employment supports given; the quality of the work environment for employer, employee and co-workers; and the cost factors and overall impact on participating state agencies.

OBJECTIVE #4 Multi-cultural Infusion

1. **Description of Objective:** Infuse culturally competent awareness and responsiveness into all activities of the Massachusetts Developmental Disabilities program.
2. **Goal:** The Massachusetts Developmental Disabilities program will be fully sensitive, competent and responsive to the culturally-related needs of all its constituents.
3. **Extent to which objective has been met:** Largely met.
4. **Expenditure for this objective:** All expenditures related to this objective are part of, and included in the three priority area objectives (#1-#3).
5. **Priority area:** All.
6. **Activities pursued for meeting this objective:**
 - a. Study or analysis Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
 - b. Study or analysis
 - c. Gathering information
 - ☐ d. Demonstration project
 - e. Outreach activity
 - f. Development of model policies and procedures
 - g. Presentation (formal or informal) to policy makers
 - h. Training for access to or for provision of service
 - i. Other similar activity to prevent developmental disabilities or to increase independence, productivity and integration
 - j. State Plan development
 - k. Activity addressing the implementation of 1990 Report findings. If activity is also a priority area, then please check both.
 - ☐ l. Coordinating activity, other than above.
 - m. Advocacy activity other than above (commenting on other State plans, State ICF/MR actions, unserved, underserved, other).

7. Summarize the activities for this objective:

✓ The Council sponsored a two day Asian American Health Roundtable: A Forum on Disability Awareness and Cultural Sensitivity. The Asian American Health Roundtable brought together member and representatives of the Chinese, Korean, Vietnamese and Hmong Cultures as well as

individuals representing various disability populations. The focus of the Roundtable was to educate healthcare providers about the subtle cultural perceptions which frequently prevent Asian American Families from seeking help, and to inform Asian Americans about healthcare resources that exist within the community. This “first time” event with support and technical assistance from the Asian American Community examined Asian perceptions and attitudes toward disabilities and persons with disabilities, a survey of traditional Asian medicine as it is used for persons with disabilities and the effects of immigration reform on access to healthcare. The forum was attended by over 75 representatives from approximately 40 statewide private and public agencies. The second day over 20 agencies and organization were in attendance to provide information translated in 4 Asian Languages and appropriate formats for Asian American consumers. The Asian American Health Roundtable has led to networking between agencies, and to the planning stages of developing policy pertaining to the healthcare of Asian Americans with disabilities.

✓ In April 1996, all MDDC priority area committees developed action plans designed specifically to recruit individuals from minority communities to actively participate on their committees. The planning session was facilitated by the MDDC Multicultural Outreach Committee. Each committee completed an assessment of their current membership (including non-council members) and developed an objective which targeted at least one cultural group from which to recruit new members. The committees documented potential resources and developed specific action plans. Although all committees began implementation in the spring of 1996, these objectives have been included under each priority area in the 1997 State Plan.

II-B. REPORTING YEAR INNOVATIVE ACTIVITIES

Innovative activities are included in Item 7 for each objective of the prior section and indicated by a ✓ in the margin.

II-C. REPORTING YEAR MAJOR ACCOMPLISHMENTS

1A. Accomplishment Title/Abstract: Health Care Access Bill

2A. How accomplishment will realize outcome: The passage and implementation of this legislation will: ensure that every child in Massachusetts through age 18 (up to 133% of the federal poverty level) will have access to health insurance (an expansion from age 12); expand coverage of children up to age 12 to 200% of the poverty level; provide medical benefits for adults who are categorically eligible for Medicaid or chronically unemployed, with income under 133% of the federal poverty level; and provide for the establishment of a drug prescription program for seniors. These benefits will be funded through an additional \$.25 tax on packs of cigarettes: the legislation was opposed by the tobacco industry, convenience store owners, and Governor William Weld.

3A. Relationship with Goals, Objectives, and Activities of State Plan: This relates to Goal II, Objective 1/Influence Health Care Policy Developments, Study Massachusetts health care legislation and other health policy developments that impact health care access or quality for persons with disabilities, and develop and communicate positions consistent with Council principles.

4A. Activities which contributed to the accomplishment: A broad-based Coalition to Improve Health Care Access of nearly 70 members worked for passage of the Health Access Act and tried to raise public awareness and legislative support. The Coalition included advocates for children, elders, and people with disabilities, Massachusetts Medical Society, provider groups, nurses, Massachusetts Teachers Association (MTA), homeless

advocates, and anti-tobacco organizations such as the Tobacco Control Resource Center and the American Cancer Society. Health Care for All (HCFA), a consumer organization dedicated to improving access to health care, built and facilitated the Coalition, sent out alerts and mailings, and held rallies. Members of the Coalition held district-based rallies and evening phone banking, which generated more than 1,000 calls to legislators before each of the three major votes on the bill—House, Senate, and the Governor's veto override. In April, the Children's Health Access Day at the State House drew 250 people with extensive media coverage. In May, at another Health Access Day attended by over 100 people, the focus was on seniors and people with disabilities, and attendees educated legislators about the senior drug prescription program provision in the bill. In June, at a rally in Northampton, the Speaker of the House first indicated support for the bill. The bill was passed by the Legislature and sent to the Governor in early July. The Governor vetoed the bill, but the House and Senate voted to override the veto on July 20.

5A. Estimated dollar volume of services created or modified or an expansion as a

consequence of activities under this program. The mandated programs are financed by a 25 cents per pack increase in the state cigarette tax which became effective on October 1, 1996. It is estimated that this will generate \$8.3 million a month, which is more than the state expects to spend on the program in the next year. Seventy percent of the new tax revenue, or \$70 million a year, will buy health coverage for children and adolescents. This could ultimately provide coverage for about 130,000 individuals—anticipated enrollment over the next year is projected at about 40,000. The Department of Public Health plans an aggressive outreach effort. State officials believe that there are about 50,000 youths between 13 and 19 who lack health insurance: it is unknown how many of these are eligible for free or low cost coverage through the state plan. The other \$30 million will go to subsidize the prescription drug expenses for low income elders in a program which will begin in July 1997.

6A. Description of accomplishment: Passage of this legislation has resulted in the expansion of health coverage for children up to age eighteen; establishment of a senior drug assistance program; expansion of coverage for the chronically unemployed; and expansion of health coverage for people with disabilities.

The legislature passed the largest expansion in health care in Massachusetts since the enactment of Medicaid and Medicare in the 1960s. Nearly 300,000 more people in Massachusetts will have access to health care as a result of the bill's passage and implementation.

1B. Accomplishment Title/Abstract: State Budget for People with Disabilities

2B. How Accomplishment will realize outcome: For the first time in Massachusetts consumers, advocates, legislators, state agency administrators can find in one document all state budget line items affecting people with developmental disabilities. The document furnished descriptions of many state budget line items including current year appropriations, the proposed appropriations changes for the coming year and information available on unmet needs. This project created more awareness of threatened budget cuts among consumers. All concerned were better able to coordinate with each other to raise the level of activism and advocacy for better services for people with developmental disabilities.

3B. Relationship with Goals, Objectives and Activities of State Plan: The ability to directly impact state funding for people with developmental disabilities relates to all objectives in the State Plan.

4B. Activities which contributed to the accomplishment: The MDDC's Legislative Committee recognized the impact that an analysis of the state budget focusing on children, created by a state advocacy group for children, had on funding for children's services. The Committee decided that a similar resource for people with developmental disabilities would be a useful advocacy tool. A request for proposals was developed and a grant

awarded to a statewide advocacy coalition, the Massachusetts Human Service Coalition. They create a very respected state budget resource called the Poor People's Budget. Working closely with the MDDC staff and our Legislative Advocacy Training Grantees, the grantee researched the historical needs of programs, the previous years budget and legislative actions affecting them, interviewed advocacy groups, state agency and private service providers concerning the existing need and produced two budget documents during the legislative session. "The Government We Lose: Increasing Access Or Creating Barriers?", a thirty -three page analysis of the Governor's budget proposal, was distributed in March 1996, and used to advocate at the House Ways and Means Committee Budget Hearings on the Governor's Budget proposal . "An Accessible Future? What Our State Budget Does-And Doesn't Do-For People With Disabilities", a forty page analysis of the House Budget proposal, was distributed in May 1996, and used to advocate at the Senate Ways and Means Budget Hearings on both the Governor's and House's Budget proposals.

5B. Estimated dollar volume of services created or modified or an expansion as a consequence of activities under this program: It is impossible to quantify the exact dollar volume of services resulting from this grant. However along with the combined advocacy efforts of many consumers and advocates significant increases in funding occurred in the state budget for individuals with disabilities including:

- \$14 million allocated for a 4 percent cost of living increase for direct care providers earning under \$20,000 per year;
- \$200,00 allocated for additional interpreters at the Massachusetts Commission for the Deaf and Hard of Hearing;
- \$2 million allocated for family supports at the Department of Mental Retardation;
- \$2 million allocated for older unserved individuals with mental retardation who are living with elderly parents;
- \$400,000 allocated for persons who are turning 22 and are Deaf and Blind;
- \$5 million allocated for a pilot project between the Departments of Mental Retardation and Education to allow students currently in private schools funded through Chapter 766 to voluntarily return to a home setting with supports;
- \$1 million allocated for Child and Adolescent Services, the first increase in years;
- Maintained three pilot programs initiated by Mass. Families Organizing for Change (funded by MDDC).

6B. Description of Accomplishment: This project produced for the first time a detailed analysis of the impact of the proposed Massachusetts State Budget on people with disabilities and their families. This project came at a critical moment in current state politics, the Governor proposed in January 1996 a total reorganization of state government including the elimination of many state disability agencies and a restructuring of the service system. The fortuitous opportunity of creating a budget document that could directly address this reorganization, its impact on disability services and the concerns this aroused in individuals with disabilities and their families, was instrumental in allowing a reasoned response to this proposal. As a result the reorganization plan was tabled relative to state disability agencies. These documents were used by people with disabilities and their families, advocates, legislators, their aides, and state agency administrators to understand what a particular program provides in its services to people with disabilities, its appropriation history in recent years, the needs as expressed by advocates for that program and what the governor's and legislature's proposals are for the next year.

1C. Accomplishment Title/Abstract: Creation of the Disability Policy Consortium

2C. How Accomplishment will realize outcome: This accomplishment will ensure that people with developmental disabilities maintain a strong voice in their efforts to impact policy decisions by providing the opportunity to express concerns and ideas about issues that affect their lives directly to the Secretary of Health and Human Services. It will also establish the basis for establishing and expanding a strong coalition of disability advocates.

3C. Relationship with Goals, Objectives and Activities of State Plan: This relates to Goal 1, Objective 4, Continuity of Effort, Activity 4 Maximize the Impact of Council funded Projects.

4C. Activities which contributed to the accomplishment: In the fall of 1995, the Weld administration announced its intent to reorganize Massachusetts government. Part of this proposal included combining a number of state agencies serving people with disabilities into a single Department of Disability Services. Despite some interest on the part of mental retardation advocates, strong opposition was voiced by smaller constituent groups, including the deaf, blind, and other disability advocates. In February 1996, the Council, through its Legislative Advocacy grantee, held an informational session for disability advocates in an effort to explain the proposal and answer questions about the impact of the proposed changes on services to people with disabilities. As a result of this meeting, a steering committee was formed to educate policymakers about the numerous problems with the reorganization proposal. Through the efforts of this group and others, the majority of changes were not passed by the Legislature.

5C. Estimated dollar volume of services created or modified or an expansion as a consequence of activities under this program: Millions of direct service dollars would have been lost as a result of the proposed reorganization. Although the proposal identified these dollars as savings resulting from administrative efficiencies, the numbers suggest that in fact every agency impacted by the changes would have had less direct service dollars in fiscal 1997 than they did in fiscal 1996.

6C. Description of Accomplishment: With the guidance of the Council's Legislative Advocacy grantee, a new disability coalition has evolved. The Disability Policy Consortium is completely consumer controlled, and the main working group consists of people who are blind, deaf, use wheelchairs, and have low incidence disabilities. This group now meets several times per month, and represents the disability community as the advisory group to the Secretary of the Executive Office of Health and Human Services. The Disability Policy Consortium has grown to include over 35 organizations in less than six months.

1D. Accomplishment/Abstract: Personal Care Assistance (PCA) Project

2D. How Accomplishment will realize outcome: In February 1996 the MDDC published a Personal Care Assistance (PCA) report for state-wide and national distribution. The report contains recommendations to improve PCA services developed by a group of "stakeholders". The report was submitted to the Commonwealth's Executive Office of Health and Human Services (EOHHS). The following recommendations were included:

- To establish a PCA advisory committee, comprised of consumers, agency representatives, providers and advocates, and to advise EOHHS on the steps needed to implement the recommendations of the Workgroup.
- To define the Personal Care Assistant as an employee and to establish a PCA pay rate that includes compensation for compulsory employment insurance. Employment insurance includes Social Security Benefits (FICA) and Worker's Compensation Insurance.

- To ensure that consumer control remains the hallmark of PCA services.
- To examine current funding sources in order to maximize the accessibility of PCA services to persons with disabilities.

3D. Relationship with goals , Objectives and Activities of State Plan: This relates to Goal 2, objective 1. Health Care Activity 1A, to Promote the Expansion of Personal Care Options.

4D. Activities which contributed to the accomplishment: The council arranged and supported a series of facilitated meetings among interested parties concerning the funding and provision of Personal Care Attendant (PCA) services for individuals with disabilities, including the elderly and children. A Request for Proposals (RFP) for facilitators was issued to conduct a series of meetings among agency representatives, advocates, PCA providers and consumers. The focus of the facilitated meetings was the question of how to provide funding for PCA and PCA-like services for unserved and underserved populations. One of the most prominent issues was the interpretation of PCA eligibility requirements as proposed by the Division of Medical Assistance.

5D. Estimated dollar value of services created or modified or an expansion as a consequence of activities under this program: No dollar value can as yet be determined. However, the disability advisory group established by EOHHS presents an excellent opportunity for increased and improved services (see 6D below).

6D. Description of Accomplishment: As a result of the combined efforts of the PCA workgroup and the Disability Policy Consortium (see Section C above) EOHHS agreed in September 1996 to convene an advisory group comprised of vendors, state agency representatives and advocates to discuss a broad range of topics regarding services to persons with disabilities, including personal care attendant services. This is the first time that disability advocates will have an opportunity to express concerns and ideas directly to the Secretary of Health and Human Services.

III. REPORTING YEAR EXPENDITURES

This includes Federal expenditures of funds awarded in previous fiscal years. Refer to next page for the breakout.

A. Type of Recipient

	<u>FEDERAL FUNDS EXPENDED</u>
1. State Planning Council	\$ 590,409
2. Designated State Agency	\$ 48,466
3. Other State Agencies	\$ 139,278
4. Protection and Advocacy Systems	\$ 5,000
5. University Affiliated Programs	\$ -0-
6. Nonprofit Private Agencies	\$ 219,226
7. Others	\$ 100,331
Total Federal Expenditures	\$ 1,102,710

B. Cost Category

	<u>FEDERAL FUNDS EXPENDED</u>
1. Federal Priority Area	
a. Employment	\$ 182,187
b. System Coordination/Community Education	\$ 424,156
c. Child Development	-0-
d. Community Living	-0-
2. State Priority Area:- Health Care	\$ 149,546
3. Analyses in Section 122(b)(5)(B)(i-vii)	-0-
4. 1990 Report Activities (other than in priority areas)	-0-
5. Planning, Coordinating & Administration of Priority Areas	\$ 298,355
6. Advocacy (other than priority areas)	-0-
7. Functions of Designated State Agency	\$ 48,466
Total Federal Expenditures	\$ 1,102,710

During FFY 1996
(Paid 10/1/95 - 9/30/96)

<u>FFY 96:</u>	
Planning (1100-1703)	15,259
(1100-1710)	260,484
Administration	
(1100-1703)	45,778
<u>FFY 95:</u>	
Planning (1100-1703)	672
+(1100-1710)	21,940
Administration	
(1100-1703)	2,688
<u>TOTAL PAID:</u>	
Planning	298,355
Administration	48,466
Total (1):	346,821

<u>Employment</u>	
FFY 94	2,500
FFY 95	85,137
FFY 96	<u>94,550</u>
	182,187
<u>Systems Coordination/ Community Education</u>	
FFY 94	163,708
FFY 95	172,891
FFY 96	<u>87,557</u>
	424,156
<u>Health Care</u>	
FFY 94	-0-
FFY 95	70,946
FFY 96	<u>78,600</u>
	149,546

FFY	Other State Agencies	P & A Systems	UAPs
1994	\$ 18,744	\$5,000	-0-
1995	\$104,585	-0-	-0-
1996	\$ 15,949	-0-	-0-
Totals	\$139,278	\$5,000	-0-

<u>Nonprofit Agencies</u>	
FFY 94	122,464
FFY 95	87,805
FFY 96	8,957
Total (3)	219,226

<u>TOTAL OF TOTALS 1,2,3</u>	
(1)	346,821
(2)	144,278
(3)	219,226

IV. STATE ACTIONS with respect to ICFs/MR during 1996

List the most significant actions the State took with respect to Intermediate Care Facilities for The Mentally Retarded (ICFs/MR), based on the following and describe the planning Council's response.

1. Based on Annual Survey Reports prepared pursuant to the SSA, Section 1902(a)(31)(C):

The Massachusetts Developmental Disabilities Council continues to receive and review the ICF/MR surveys and Plans of Corrections that the Health Care Financing Administration conducts. The agency in Massachusetts that continues to have the authority and responsibility to certify facilities to participate in the ICF/MR program is the Massachusetts Department of Public Health, Division of Health Care Quality, which conducts certification surveys and independent professional reviews on an annual or more frequent basis as needed. All seven facilities were certified as meeting the standards of the federal Health Care Finance Administration (HCFA) by the end of calendar 1996.

2. Based on correction and reduction plans prepared pursuant to the SSA, Section 1922:

During the last federal fiscal year, facilities were at times out of compliance with the active treatment standards. All deficiencies were corrected and are in compliance with the standards.

3. Significant actions other than above:

The Governor's Commission on Mental Retardation works cooperatively with consumers, their families, concerned citizens, the Department of Mental Retardation (DMR), and other agencies to improve the mental retardation system. As advocate for all people with mental retardation in Massachusetts, its 3 staff and 9 gubernatorially-appointed members address individual and group problems which are not resolved through usual processes, review the quality of services and public policies as they affect all persons with mental retardation, hold public hearings, and make recommendations to the Governor. The Commission has identified the waiting list issue as a major priority. On September 24, 1996, the Commission held a state-wide public hearing on enhancing community inclusion for people with mental retardation. Many people from around the state presented testimony on specific strategies to enhance inclusion at home, school, work, in recreation and in spiritual life. A consumer member of MDDC, Sandy Milyko testified on behalf of the Council.

Seven large facilities (Fernald, Templeton, Dever, Monson, Hogan, Wrentham and Glavin) serve approximately 1,835 residents of the total 24,221 people who are in some way assisted by DMR. In DMR provided residential care to approximately 6,941 people. While Massachusetts collected \$45 million in federal reimbursements in 1992, it collected approximately \$170 million in federal reimbursements under the Home and Community Based Waiver Program in 1996.

The Department of Mental Retardation held three public hearings around the state with respect to the projected operational status of DMR State Schools and Developmental Centers. The FY1997 State Budget had outside budget language requiring DMR to develop a five year plan regarding the status of its facilities. The MDDC submitted testimony supporting independence, productivity and inclusion in the most suitable environment for each person.

V. REPORTING YEAR STATE PICTURE

V-A. REPORTING YEAR INDEPENDENCE, PRODUCTIVITY & INTEGRATION

Department of Mental Retardation Waiting List: The Department issued an action plan on September 20, 1996 to reduce their waiting list. "Facing the Waiting List Challenge: Responding to the Needs of Individuals and Families", represents for DMR a significant first step in what they call a collaborative effort to re-engineer public policy to help families in need. Currently there are over 3,000 individuals waiting for residential and/or day services. DMR estimates that the waiting list will increase at the average annual rate of 13%. 86% of those on the current waiting list are in need of residential services. The most significant increase is the numbers of individuals turning 22 and individuals with caregivers 60 years of age or older.

Although DMR has reorganized resources and employed new strategies to address the waiting list, they recognize that additional resources are needed and have announced a three year plan to accomplish this. They will redirect facility resources as consolidation continues; expand overall revenue by pressing for revision of federal law to allow deinstitutionalized individuals receiving sheltered and supported work to be included in the federal waiver; ensure that funding for Turning 22 and Family Support continues at least at current levels while seeking an additional appropriation targeted to those on the waiting list; utilize a capital bonding "lease back" strategy; create a "facility placement reserve" by using a percentage of revenue from the federal waiver to accelerate placements; and apply 50% of excess revenue to address the waiting list.

DMR will also pursue a long term plan to eliminate the entire waiting list and reduce the numbers added each year by expanding Turning 22 funding, promoting earlier transition planning and funding family supports.

State Budget Language Concerning Transition From Institutions to Community: The State's FY1996 budget contained language restricting the movement of people from institutions into the community. The Governor vetoed this section after the Council, Arc Massachusetts and other advocates asked the Governor to reject this section. However, the veto was later overridden by the State Legislature at the close of the 1995 session. A lawsuit was filed on behalf of institutional plaintiffs, and the FY1997 budget contained outside budget language prohibiting DMR from taking any action to reduce the client population at institutional facilities that it currently manages or operates, or taking any other steps to close any of those facilities. But the language continues to avoid litigation on behalf of any individual, stating that "nothing herein shall be construed to prevent the transfer of any client from a state facility to a facility staffed by state employees or to a community placement when the transfer is both clinically warranted as determined by the client's individual service plan and approved by his guardian."

Development of Five Year Plan For State Operated Facilities: The state budget directed DMR to develop a five year plan regarding the projected operational status of all its facilities. The plan shall include the numbers of current resident in state schools and centers for persons with mental retardation; the current average cost; an analysis of the availability of community based settings, of projected

community placements over five years, and of the cost of developing and maintaining such community-based placements over a five year period. The Plan shall compare the Massachusetts' costs with other states, projected savings from any consolidation or closures and plans for savings, and several other analyses.

Mental Health Managed Care: Contracting between state agencies and private corporations for managed health care services is a continuing trend in Massachusetts. The Division of Medical Assistance entered into a service agreement with Massachusetts Behavioral Health Partnership (MBHP) to control medically related costs for persons eligible for Department of Mental Health Services. MBHP will approve all inpatient and out patient service for persons with mental illness. The role of the DMH is to oversee the appropriateness and the quality of mental health service provided to Department consumers. Advocates and mental health consumer continue to express concern about the contract stating that access and quality of mental health services is decreasing.

PCA Choice: There is a growing consensus among consumers, providers, advocates, as well as regulating agencies, that individuals working as PCAs, who are currently consider to be independent contractors, more closely meet the criteria for employees. A significant number of Massachusetts PCA consumers expressed concern that in addition to the challenges they already face in their daily lives, the implication of employer liabilities push them beyond the reach of their financial and/or managerial capabilities. Further, the hourly rate of pay authorized by the Division of Medical Assistance for an individual PCA is insufficient to cover the additional costs for worker accident and disability insurance (Worker's Compensation), Social Security and Medicare (FICA) and Unemployment Insurance.

Person Centered Planning: The increasing number of individuals with disabilities who live in the community is challenging the service delivery system. One method developed to meet this challenge is to involve greater numbers of citizens in the planning and delivery of services for these people with the hope that people in the community will remain involved in the lives of people with disabilities. This is called Person Centered Planning and it includes the consumer's family, service providers, and interested friends and neighbors in designing an array of services based on an individual's needs and dreams. The Department of Mental Retardation will then issue an RFP for the desired services to the vendor community. Vendors are selected on their ability to provide the specified services and to maintain family and community involvement with the individual. DMR initiated a pilot project about two years ago which uses person centered planning to develop new community services. The Departments of Mental Health and Social Services are contemplating implementing similar models.

Health Care Access: As of June, 1996, the number of uninsured people in Massachusetts has increased to about 700,000 from about 455,000 in 1989, when the Universal Health law was passed under Governor Dukakis. In six years, the number of children under age 18 in the state without health insurance jumped more than 75% (from 90,000 in 1991 to more than 160,000). The implementation of the Health Care Access bill would do much to address this problem, especially in the area of children and people with disabilities.

Special Education: There has been a backlash against the costs of special education throughout the state and nation. On June 10, 1996, "60 Minutes" presented an inaccurate portrayal of the costs for special education, focusing only on a few extreme cases. The program was an unfair representation of special education and IDEA, as it failed to provide any balance to the issue by presenting any success stories. The Council protested the one-sided coverage, and requested that 60 minutes conduct a follow-up story. Receipt of the Council's correspondence request was never acknowledged.

In Massachusetts, the Speaker of the House has prioritized "reform" of special education for the upcoming year, indicating that cost control is a priority. Various pieces of legislation have been proposed which put at risk the state's "maximum feasible benefit" provision for students in special education. There is a clear division between parents of children in special education and parents of children in regular education, and the continued focus on costs may serve to widen this division. Unless and until advocates can focus public perception on the long term positive impact, special education will remain at risk.

Budget Campaign: As a result of "Campaign 23,855", led by ARC Massachusetts and joined by many other advocacy groups, certain gains were made in the 1997 State Budget, including money for a small raise for direct care workers, older unserved, turning 22 populations, and an increase in Respite Care/Family Support of \$3 Million (to \$35,404,204). This latter increase will enable the DMR to continue its efforts in flexible family supports. In addition, starting with state FY 1996, DMR began a grant program for innovative family support projects.

Family Support Pilot Projects: The 1996 state budget mandated the creation of three family support pilot projects. The 1997 state budget extends these pilots through December 1996. In October 1995, a Memorandum of Understanding was signed between DMR, the lead state agency, and Massachusetts Families Organizing for Change, establishing Regional Pilot Projects. MFOC is now a credible and viable organization and significant force in the effort to obtain support services for individuals and families. The primary goal of the projects was: "to demonstrate that providing families with the necessary resources (money, technical assistance, broker) is the most effective way to ensure that children will be able to live with their families." The pilot projects were sponsored by the state legislature as a means of testing the principles and values embodied in the proposed legislation.

Pilot projects were put in place in three regions, and a total of 21 children and youth with disabilities—ranging from pre-school age to age 22—and their families received supports through these projects.

Southeast Region: Used a broker system with families with a member in transition (turning 22); involves a whole life/person centered planning approach. Three families have been served. Whole life planning was utilized, and the broker worked with the families. In addition, the pilot provided some funds to the family. This region hopes to add new families in FY 1997.

Northeast Region: Used a broker system to work with families with a member at risk of out of home placement. This pilot served 13 families with a variety of needs, ranging from information to respite. There has been a lot of flexibility; a broker helps the families. Some changes are planned for the second phase.

Central Region: This project focused on children with multiple issues; and the use of associate families to work with those who are at risk of out-of-home placement. Two of the five families utilized associate families. A family driven, family planning session similar to whole life planning (person centered planning) examined individual needs and provided medical advocacy as well as education. Phase two will continue with the same families and add up to five new ones.

As a result of these projects, children with disabilities at risk of leaving the family home because of lack of support are at home with their families. Parents under enormous stresses due to lack of support have found their family environment strengthened, and new hope for the future. Young people with

disabilities have found their own purpose and a plan for the future. Children with very complex medical needs have been supported to live at home with their families. Both children and families have had access to planning support which has given them a vision for their future. The pilots demonstrated the importance of flexible funding and widening the access to and use of such a funding arrangement may be necessary if the outcomes for individual and families are to be more widely achieved.

Family Support Legislation: MFOC has filed an Act to Support Citizens with Disabilities and Their Families for five years. The Council has made the bill its priority bill for four years. Each year, the bill has stalled in the House Committee on Ways and Means, due to concerns about potential costs. This past year, MFOC filed the bill in both the House and the Senate, and worked hard to educate legislators about the bill and the issues. Due to the interest of the new Chair of the Senate Ways and Means Committee, the bill passed through the Senate in late June, just before the close of the legislative session. The Chair of the Senate Ways and Means Committee has promised to work with MFOC on a refile for the next legislative session.

Workforce/Welfare Reform: State welfare reform has introduced a new set of work rules requiring that able bodied heads of households with school age children, who receive Transitional Assistance to Families with Dependent Children (TAFDC), either work at paid employment or volunteer 20 hours of Community Service per week at a non-profit organization. The only exception categories include a parent with a disability who seeks exemption from the work rule, or families with two parents that qualify for TAFDC because one parent has a disability. It is anticipated that 18,000 adults receiving TAFDC will be affected by the new work rules welfare reform. Through legislative support and various interagency agreements on going efforts have been established to assist TAFDC recipients to receive Job Search Training/Job Development and placement.

The Department of Employment and Training (DET) operates the "Skills Plus" Program, which is funded by a budgeted legislative line item in the vocational/pre-vocational training category. Skills Plus is a short term (28 days) vocational training program for Job Search. TAFDC recipients enrolled in this program are assisted from the start of school to the actual hiring stage.

The Employment Network program operates through an interagency agreement between DET and Massachusetts Transitional Assistance (MTA). This program assists TAFDC recipients in job development and placement, and operates through the various Department of Transitional Assistance Offices.

School-To-Work: Massachusetts was one of the first of 40 states to be awarded a venture capital grant under the School to Work Opportunities Act (STOWA), which is designed to meet the standards set by the Goals 2000 Educate American Act. The state is committed to building a whole school to work transition system, designed to utilize the workplace in developing broad academic skills. This design is achieved by bringing the business world into the classroom to assist educators in understanding the broad academic skills which are essential for success in the workplace. Under the School to Work model, business is instrumental in changing the way schools operate. Through this design, the students are exposed to the workplace, gaining a better understanding of the nature of work. This design also reinforces the concept that time spent in a structured work environment can be appropriate in meeting underlying classroom academics.

Through the School to Work program, Massachusetts has placed a premium on learning and mastering skills for career success. The program also provides the local community with an opportunity to organize its available employment resources, and to create opportunities for job shadowing, internships

and work experiences as part of every students educational program.

One Stop Career Centers: In FY 1996, Massachusetts opened seven One Stop Career Centers, with the expectation of opening twelve additional centers. State agencies receiving federal funding for a variety of employment and training programs have contributed a total \$12 million into a new integrated funding stream for the operation of the first career centers. The Department of Employment and Training, the Department of Transitional Assistance, The Department of Education, the Industrial Services Program, the Massachusetts Rehabilitation Commission, the Massachusetts Division for the Blind, and each local Service Delivery Area are moving resources into the new One-Stop Career Center system. The goal is to restructure the existing workforce development system into one which is market driven, customer/consumer driven and is outcome and performance based.

Guided centrally by the Mass Jobs Council, each One Stop Career Center is operated by collaborative partnerships of private and public entities, and is administered by the local Regional Employment Board (REBs). Massachusetts has chosen a competitive model, which means competition not only in bidding for the privilege to operate centers but against the traditionally established employment /job training providers such as Department of Employment Training. This trend to consolidate services and supports has both positive and negative implications. The disability community is primarily concerned about access. Not only physical access to the sites, but access to the technical resources provided at the centers. There is also concern about providing disability representation at local level, in both policy and practice to maximize service options for individuals with disabilities seeking employment.

From the business perspective, a recent survey of 200 Massachusetts businesses revealed that 82% would utilize One Stop Career Centers, while only 3% said they would use any of the existing public agencies in Massachusetts.

State Reorganization Plan: Last winter, the Governor proposed a radical reorganization plan that would have eliminated 7500 state jobs for an alleged savings of \$650 million. The proposal would have combined many of the disability agencies into a Commission, thereby diluting their autonomy. Advocates rallied to defeat the proposal, and their hard work was rewarded by the rejection of most of the proposal's components by the Legislature. However, some changes did occur that will affect people with disabilities. The Executive Office of Health and Human Services was reorganized into three bureaus: Family Services, Disability and Health, and Health Care Financing. It remains to be seen if the Governor will continue his efforts to consolidate individual disability agencies.

Direct Care Workers Salary Increase: Direct care workers finally saw an increase in their wages for the first time in nine years. Approximately \$14 million was budgeted to increase wages for those earning less than \$20,000 per year. Unfortunately, wages are still inadequate to provide a decent standard of living, so problems with high staff turnover at human service provider organizations will continue.

Other State Budget Victories: Additional funding was allocated in the FY 97 budget for the following:

- additional interpreters at the Massachusetts Commission for the Deaf and Hard of Hearing;
- additional family support services for DMR;
- older unserved individuals who are living with elderly parents;
- persons who are turning 22 and are deaf and blind;
- a pilot project to move people currently in private schools funded through Chapter 766 to a home

setting with supports;

- maintaining 3 pilot programs initiated by Massachusetts Families Organizing for Change.

Hospital Mergers: With major changes in the health care industry, many of Massachusetts' hospitals are merging with other area hospitals or agreeing to acquisitions to assure their survival in an uncertain future. This past year Boston City hospital, the area's largest public hospital, was acquired by University Hospital to become "Boston Medical Center". Previously, Boston City Hospital was the largest source of free care to low income patients in Eastern Massachusetts. Advocates fear that privatization of the hospital will result in an end to free local care. Another troubling trend is the acquisition of Massachusetts non-profit hospitals by for profit health corporations. A major hospital in Worcester was recently acquired by a for-profit, and the same corporation is discussing a possible acquisition with another major Boston hospital. People with disabilities tend to incur higher medical expenses than the general population, so they are the most vulnerable to the cost cutting initiatives by for profit health care organizations.

Resources Exhausted to Maintain Status Quo: Many of the existing disability advocacy resources were exhausted this year in the struggle to maintain the status quo. People with disabilities and advocates focused much of their time and energy on preventing further cuts in programs by both the Federal and State governments. The disability community rallied against Congress' proposed cutbacks of DD funding, Medicaid and other disability programs as well as Massachusetts' proposed reorganization of human service agencies. With so many resources expended on efforts to maintain the current level of funding, progress in moving the disability agenda forward was limited.

V-B. REPORTING YEAR ACTIVITIES FOR UNSERVED AND UNDERSERVED GROUPS

Massachusetts citizens with disabilities who have been unserved and underserved include children, elders, minorities, the homeless and individuals with low incidence disabilities.

Children

Shaken Baby Syndrome: The Office of Disability Prevention (at the Department of Public Health) has examined the issue of "Shaken Baby Syndrome" (SBS) in collaboration with the Massachusetts Committee for Children and Youth. SBS is associated with injuries caused when an infant is vigorously shaken, usually by an adult: 20 to 25 percent of its victims die and most survivors maintain brain damage with resulting cognitive and sensory impairments. The Massachusetts Committee for Children and Youth has recently issued materials on Shaken Baby Syndrome as part of its campaign, "Never Shake a Baby." It produced PSAs for television which have been aired on this theme; and a brochure was recently released which includes tips for parents on why a baby could be crying and on how to avoid abuse. DPH will distribute these brochures in FFY 1997 through different channels, such as WIC, Early Intervention and Healthy Start.

Child Care Resource and Referral Centers (CCR+Rs): This past year, the institute on the transition of young children traditionally sponsored by the Department of Education and Early Intervention included outreach to day care providers and parents, and more people were involved in the training than ever before. Each of the 13 CCR+Rs hosted a "Working Together Interagency Collaboration Forum"

for children with disabilities. Over 1000 people attended the program, which was presented from the parent and family perspective. The enhanced program for families with children with disabilities began in state Fiscal Year 1996. During this time, the Office for Children transferred resources to the Department of Transitional Assistance for vouchers for low income families (with children with disabilities). Approximately sixty families with a child with disabilities were moved off the waiting list ahead of other families. For state fiscal year 1996, there were 10,553 "public calls" (from parents, families) to the child care resource and referral centers. Of this number, only 3% (or 320) were from families with children with disabilities. It is suspected that many parents of children with disabilities do not know that day care is available due to the requirements of the Americans with Disabilities Act. CCR+Rs provided enhanced services to 37 families with children with disabilities, and helped them to find child care in Boston and the Greater Boston Area. In addition, they supported children in both subsidized and non-subsidized placements.

PCA Services for Children Residing with Family Members: Since the Division of Medical Assistance has become more strict in implementing the PCA program, it seems that many children (and others) who need PCAs but who are residing with their families are being denied this service. Legislation has again been filed for the upcoming legislative session in 1997 to protect PCA users from interruption and denial of services due to changes in administrative interpretations of eligibility, and procedures which result in less access to PCA services.

Children and Young Adults Over age 22 in Pediatric Nursing Homes: For many years, the state has funded about 250 beds in four pediatric nursing homes. For the first time, there are several empty beds. However, the problem of children turning 22 and remaining in nursing homes has not been resolved. At least 78 young adults over age 22 still reside in pediatric nursing homes, due to a lack of alternative programs to which they can move.

SSI for Children: Because of welfare reform changes and a new (and stricter) definition of disability for children, the Social Security Administration is no longer required to do individualized functional assessments for children. It is expected that about 300,000 children in the nation will have their cases reviewed to see if they are still eligible for SSI. Those that lose SSI may also lose Medicaid. Many of these children, if not most, have developmental disabilities. In Massachusetts, there are about 17,000 children on SSI, of which about 5300 would require review under the new rules. The families of the 5300 children should have or will be receiving a notice that as of January 1997, their child will be reviewed. Some may receive a grace period up to July 1997. In Massachusetts, if a child loses SSI, there is a provision to conduct a redetermination to see if the child is eligible to continue on Medicaid in another category.

Elders

CARDS Project: The Coordinated Aging, Rehabilitation and Disability Services (CARDS) Project, funded by the Administration on Aging (AOA) and the Executive Office of Elder Affairs (EOEA), was to be a three year project which began in 1995. Its goal is to design a replicable model for a long term care system for elders and adults with disabilities. The Project held a conference in November 1995 to convene people to review and discuss significant issues identified by thirteen focus groups in the areas of health care, quality of life, employment, information and referral, system delivery, transportation, personal assistance services, serving multi-cultural populations, communication, and housing. The Project compiled a comprehensive inventory of services for elders and people with disabilities, and presented system change recommendations in the Blueprint for Autonomy, disseminated to the

Governor, legislature, media, and local and national aging and disability networks. Most of year two of the project was spent implementing some of the suggestions from the conference. Although the project did not receive a third year of federal funding, EOEA has made a commitment to see the project to a conclusion.

The project also provided extensive training of elder service providers on disability issues and the Americans with Disabilities Act. Project staff participated in several conferences to present CARDS findings about what consumers want and need from the system. Several EOEA disability projects are being implemented in FY 1997, including:

- using low tech equipment as a home care service (to start soon—as of Dec. 96);
- forming an Elder-Disabled Task Force of home care corporations and EOEA staff which has started working on systemic solutions to service needs of elders with disabilities;
- setting up 5-10 self-help groups for elders (on depression and depression screening)—based on a peer counselor model;
- designing and conducting, with independent living centers, training for home care case managers about the availability of disability services, and networking on the local level between ILCs and home care corporations.

CARDS is negotiating with DMR for some long term joint projects, including a project to address the needs of elders with mr who are placed in nursing homes or who are at risk of such placement due to lack of community-based services and a project on aging caregiver issues.

Homeless People with Disabilities

People with Head Injury: The Statewide Head Injury Program of the Massachusetts Rehabilitation Commission (MRC) received continued funding to work with shelters in order to serve people with head injuries. This funding continues stabilization activities to provide long term supports for the homeless. Provisions include identifying homeless individuals with head injuries in shelters, issuing them section 8 certificates and providing the necessary supports such as PCA, Interpreters for individuals with deafness. The \$83,395.00 is a targeted outreach program through Emergency Shelter Grant (HUD grants)

Shelter Accessibility: MRC has expanded its supportive living program, working with shelters for individuals to enhance accessibility (physical and for those with environmental illness). This effort is being conducted under an emergency shelter McKinney Grant through the independent living centers, having them part of the individual's long transitional living plan.

Minorities

Asian American Health Roundtable: The Council sponsored a two day Asian American Health Roundtable: A Forum on Disability Awareness and Cultural Sensitivity. The Asian American Health Roundtable brought together member and representatives of the Chinese, Korean, Vietnamese and Hmong Cultures as well as individuals representing various disability populations. The focus of the Roundtable was to educate healthcare providers about the subtle cultural perceptions which frequently prevent Asian American Families from seeking help, and to inform Asian Americans about healthcare resources that exist within the community. (See Section 2A, Objective 4)

Outreach and Leadership Training for Minority Populations: MetroWest Center for Independent Living in cooperation with the Statewide Independent Living Council (SILC) received a DD Council small grant to develop outreach and leadership training to minority underserved populations. The grant is designed to organize a one day conference to build leadership skills in staff from multicultural backgrounds, representing independent living centers in Massachusetts.

Low Incidence Disabilities Groups

The publication of the original Low Incidence Disabilities Guide was the major product of a grant funded by the Massachusetts Developmental Disabilities Council (MDDC) in 1991. However, six years later, much of the information is outdated. The MDDC has received numerous requests for an updated version of the guide. As a result, the Council is currently researching and collecting the most current information available. The resource guide offers consumers access to products and services unique to their disability. The information contained in the guide is useful not only to consumers and their families but professionals, organizations and school systems as well. The new guide is scheduled for dissemination in the spring of 1997.

V-C. REPORTING YEAR PRIORITIES IN STATE

Despite the many successes over the past year, the continuing theme within Massachusetts remains cutting costs and reducing government services. Maintaining quality services to people with developmental disabilities is at best a secondary consideration. The disability community continues to lack a direct voice to the Governor. However, on a positive note, due to the creation of the Disability Policy Consortium, disability advocates have an opportunity to express concerns and ideas directly to the Secretary of Health and Human Services. It is hoped that this is a first step in reaching the ultimate goal of representing disability issues at the Cabinet level.

State Reorganization Plan: Last winter, the governor proposed a radical reorganization plan that would have eliminated 7500 state jobs for an alleged savings of \$650 million. The legislature approved a pared down version of the plan that cut 40 jobs and yielded \$8 million in savings. The governor eliminated the Department of Education as a secretariat level, and downgraded four other secretariats to divisions.

State Budget: State budget increases for the disability community this year include allocating additional funding as follows:

- \$14 million was budgeted to increase the wages up to 45 for direct care workers earning less than 20,000 per year;
- \$200,000 for additional interpreters at the Massachusetts Commission for the Deaf and Hard of Hearing;
- \$2 million for family supports at the Department of Mental Retardation;
- \$2 million for older unserved individuals who are living with elderly parents;
- \$400,000 for persons who are turning 22 and are deaf and blind; and
- \$5 million for a pilot project to move people currently in private schools funded through Chapter 766 to a home setting with supports;

Additional budget provisions included:

- Maintaining 3 pilot programs initiated by Massachusetts Families Organizing for Change;
- Establishing a 5 year planning process for long term care facility review;
- Establishing a study commission to look at all laws and regulations affecting the siting of group homes; and
- Establishing a task force on special education.

Special Education: Please see Section A. for a discussion of the threats to special education in the nation and in the state.

Pediatric Nursing Homes: This year, there are at least 78 “children” who are 22 or over residing at these nursing homes. This problem has been long-standing. (Please see Section V.B. for more discussion.)

Health Care Access Bill Implementation: As of December 1996, the bill has not been fully implemented. The Division of Medical Assistance must produce a budget neutrality document, originally anticipated to be done by mid-November. Now expected by the first of the year, this document will examine different options for coverage under the Health Access Bill. If the state were to expand coverage for children up to 200% of the poverty level, the state would need to go to the federal government for approval or a waiver amendment. In addition, there needs to be an appropriation from the legislature for the funding (either through a supplemental budget for FY 1997 or in the state FY 1998 budget). The Governor requested a supplemental budget in October 1996, but it has not passed. The Department of Public Health has begun to implement the expansion of children’s coverage up to age 19 with extra monies from an existing account.

DMR Waiting List: Please see Section V-A for discussion of plans for providing services to people with mental retardation who are on the waiting list.

Moving People with MR From Institutions to the Community: Please see Section V-A for discussion of related budget language and the Five year Plan for moving people with metal retardation to the community.

V-D. REPORTING YEAR POLICY REFORM IN STATE

Health Care Access Bill Implementation and Potential Changes to the 1115 Waiver: Last year’s Annual Report described the 1115 waiver which was approved by the Health Care Finance Administration in 1995. Its purpose was to increase the numbers of low-income citizens who are covered by “Medicaid type” health insurance benefits. The implementation of the 1115 waiver would expand access significantly for many people. There were four components:

1. A New State Benefit Plan for low-income adults whose income is less than 133% of the poverty line.
2. A two-part “Insurance Reimbursement Program,” none of which was included in the Health Care Access Bill. (The first part of the program would provide Employer tax credits, while the second part would provide insurance payments (up to 10% of the premium) for employees that earn up to 200% of the federal poverty level.)

3. An expansion and simplification of eligibility for the Medicaid program for people with disabilities whose income is under 133% of the poverty level and for single parent families.
4. An expansion of the CommonHealth program to adults with disabilities who do not now meet the work hour requirement (40 hours per month), who would otherwise have to spend down their resources.

During the summer of 1996, Rep. McDonough and Senator Montigny submitted the Health Care Access bill. The Governor submitted his own health care bill, which did not pass. The Governor vetoed the Health Care Access bill because it increased the cigarette tax. His veto was overridden by the Legislature. The bill excluded the insurance reimbursement program and the employer tax credit which had been in the original waiver.

The Children's Medical State Plan (CMSP) program expanded to cover children up to age 19 and under, and a senior pharmacy assistance program was created for low-income seniors over age 65. The Department of Medical Assistance (DMA) must prepare a budget neutrality document, which it hopes to submit by the end of December 1996. It will examine different options for coverage, including expanding coverage to children up to 200% of the poverty line. However, if it expands to 200% of the poverty line, the state must apply for federal approval or a waiver amendment. If the state maintains the coverage only for people at 133% of the poverty line, no changes are required.

The Legislature must appropriate funding for the various pieces of the bill, either through a supplemental budget for FY 1997 or in the state budget for 1998. The Governor requested a supplemental budget in October for the senior pharmacy program and children's coverage, but it has not yet passed. The state has started the CMSP expansion with extra money from an existing account.

DMA needs open enrollment periods in February and March for the senior pharmacy assistance program which is to begin in July 1997. It is hoped that the budget request will pass, because lack of funds could hold up program implementation. This program would be operated by the Executive Office of Elder Affairs.

Welfare: President Clinton signed the Welfare Reform Bill (PL 1045-193) August 22, 1996, which gives the individual states flexibility in the management of their welfare programs. This national welfare reform, combined with the Massachusetts reform bill passed in February 1996, will have the effect of cutting Children's SSI, imposing a work requirement to all heads of families, limiting welfare to two years cash assistance within any five year period, and eliminating most federal benefits to legal immigrants. The new welfare rules for Massachusetts are slated to go into effect December 1, 1996.

Within Massachusetts there are approximately 16,000 SSI eligible children of that number, 5,367 children, with severe disabilities, are SSI recipients based on individual functional assessment (IFA). Under the new disability standard, a child must have a "medically determinable physical or mental impairment which results in marked and severe function limitations". It is difficult to estimate the numbers of children, who will qualify or re-qualify. The federal Welfare Reform law changes the SSI eligibility for low income disabled legal immigrants. Virtually eliminating all federal benefits to legal immigrants until they attain citizenship. But at the state level under the flexibility discretionary provisions, some legal immigrants could be eligible for EAEDC, Medicaid, or TAFDC, Massachusetts could design its programs to include non-citizens. It is estimated that under the Massachusetts Welfare Reform law, new work rule provisions will require heads of households receiving TAFDC with school

age children to find paid employment or volunteer 20 hours per week in Community Service.

Executive Order 384: To Reduce Unnecessary Regulatory Burden: Pursuant to this Executive Order, every state agency undertook a review of every regulation under its jurisdiction currently published in the Code of Massachusetts Regulations. As of September 30, 1996 over 200 regulations were revised and 180 eliminated. Consumers and advocates for people with developmental disabilities expressed their concerns about the possible negative effects this may have on individuals with disabilities especially with special education and other services provided by many state agencies. The Executive Order had no authority over regulations promulgated by the Board of Education. The Council expressed its concern to the Department of Mental Retardation and other state agencies when regulations were reviewed.

Budget Language Affecting De-institutionalization: See Section V-A for a discussion of the FY 1997 budget language concerning the closing of state facilities.

DMR Waiting List: See Section V-A for a discussion of plans for provide services to people with mental retardation who are on the waiting list.

V-E. REPORTING YEAR ADVOCACY IN STATE

Statewide Independent Living Council (SILC): In the fall of 1995, the Massachusetts Statewide Independent Living Council (SILC) brought Gina McDonald, President of the National Council on Independent Living, to train SILC members and the independent living (IL) community on Independent Living philosophy and advocacy. This set the stage for an active year highlighted by legislative advocacy trainings around these skills.

The SILC advocated for long overdue increases in, and more equitable funding for deaf and hard of hearing independent living services in the Massachusetts Commission for the Deaf and Hard of Hearing budget. The SILC was actively involved in advocacy regarding the impact of the proposed reorganization of state government on disability services, and is a member of the resulting Disability Policy Consortium (see below).

The Independent Living Centers encouraged voter participation and voter registration. These efforts culminated in SILC sponsoring Justin Dart's non-partisan Justice '98 visit to Massachusetts. SILC also supported many advocacy efforts spearheaded by SILC members. For example: efforts to improve access to the town of Spencer, the battle to secure an accessible and community-based location for Granada House, a substance abuse facility, which has been a leader in service provision for persons with disabilities.

In FFY 96, the MDDC became an Ex Officio Member of the Statewide Independent Living Council (SILC), serving as a member of its Evaluation Committee. Of paramount concern to the SILC and other member organizations of the state's disability community was the proposed state reorganization plan. SILC cosponsored a meeting at the Massachusetts Archives to consider the impact, the governor's restructuring of state government would have on people with disabilities. Two subsequent rallies were held at the State House, which were a major influence in charting a "course correction" in the reorganization plan and establishing a Disability Policy Consortium with access to an Undersecretary of the Executive Office of Health and Human Services (EOHHS).

The SILC applied for two grants from the Massachusetts Developmental Disabilities Council (MDDC) under the non-profit status that Metrowest Center for Independent Living holds. Both grants were funded. One project is designed to hold an Independent Living Day at the State House to inform state Legislators of issues impacting independent living. The second project plans to conduct minority outreach and leadership development within the independent living community. (See Section V-B)

The MDDC continues to work with the SILC Evaluation Committee in developing a Consumer Satisfaction Survey which is consistent for all IL's in collecting and tabulating results and will tie into performance-based contracting issues.

Mass Commission Against Discrimination (MCAD): The Massachusetts Commission Against Discrimination (MCAD) is a state agency that enforces the state's anti-discrimination laws with regard to employment, housing, credit and public accommodations. The laws prohibit discrimination based on race, color, religious creed, national origin, ancestry, age, sex, sexual orientation, and disability. The Massachusetts fair housing law also prohibits discrimination on the basis of children, public assistance reciprocity, marital status, and veteran/military status.

About 5000 complaints are filed in either the Boston or Springfield offices of the MCAD. The same number of complaints are resolved during the year. The public service that the Commission provides is in the investigation and resolution of cases where probable cause has been found and conciliation failed.

Over 100 public hearings are held during the year. Of the 5000 complaints filed each year, 20% are filed on the basis of disability. If the case is jurisdictional under federal law the MCAD has a contract to investigate and resolve these cases under Title VIII for housing cases and ADA for employment. The federal agencies then lends weight to a finding at the MCAD.

Disability Policy Consortium (DPC): The Disability Policy Consortium is comprised of consumers who are blind, deaf, use wheelchairs, people with chemical sensitivities and with low incidence disabilities. This group came together as a response to the reinventing government proposal in the FY 1997 House 1 Budget, which attempted to bring the disability community together into one single agency. The DPC on two giants within the Massachusetts Human Services System: The FY 1997 budget and the issue of Personal Care Assistance. Through a working committee with representatives of each consumer group, a budget agenda was developed highlighting the needs of each constituency. This consumer body agreed that it would advocate for the needs of the three groups and stay together as a movement.

The DPC meets monthly with the Deputy Secretary of Health and Human Services, and regularly with policy leaders in the Human Services system. They testify as one voice at significant public hearings and provide clear and well developed material at each of these events. Through funding from the Massachusetts Developmental Disabilities Council, sign language interpreters, materials in Braille and phone hook ups for persons with chemical disabilities are made available for each meeting. This is the first time that such a diverse community has come together as a movement. These consumers are knowledgeable, disciplined, and becoming a major force in the human services advocacy community in Massachusetts.

Governor's Commission on Mental Retardation: The Governor's Commission on Mental Retardation has a challenging mission which combines policy analysis, development, advocacy, and complaint resolution. While the Commission has a formal complaint process to promote problem

resolution for individual consumers of DMR services, most of its activities examine systematic issues. These issues include persons waiting for services for prolonged periods of time as well as children and adults with mental retardation who are inappropriately placed in nursing homes. Over the course of its initial three year term, the Commission staff completed 13 reports on topics ranging from day and clinical services to voluntary state-family cost sharing. Six public hearings were held on such issues as; the waiting list, clinical services, housing, transportation, nursing homes, and inclusion. The Commission sponsored three conferences on risk/safety issues, managed care, and the new definition of MR. The Commission is to begin a second three year term in 1997.

Governor's Inter-Agency Coordinating Council on Disability Services: The Governor's Inter-Agency Council on Disability Services, whose membership is comprised of heads of all major disability agencies, researched and reviewed all state disability programs. The Council produced and distributed 2 reports recommending ways in which the Commonwealth could make those programs more cost-effective, efficient and user friendly. The Council also provides a regular forum which brings agency heads together for the purpose of implementing systematic improvements.

Governor's Advisory Commission on Disability Policy: The Governor's Advisory Commission on Disability Policy, an advisory commission comprised primarily of consumers, did extensive advocacy work on a number of legislative and programmatic issues to expand the rights of people with disabilities. Members advocated by writing letters to the Governor, submitting comments on regulations to the appropriate agencies, and testifying at legislative and public hearings.

Medicaid Defense Group: Passage of the Health Care Access Bill was this year's primary focus of the Medicaid Defense Group. Particular emphasis was placed on insuring that the language in the bill was inclusive of people with disabilities.

Massachusetts Human Services Coalition: The Massachusetts Human Services Coalition published three new books designed to increase advocacy for better services to people with disabilities in the Commonwealth. The first, *The Government We Lose*, provided data for disability advocates fighting a state reorganization plan. The second, *An Accessible Future*, supported intense lobbying efforts to increase state funding for disability services. The third, *Massachusetts Billions*, describes threats to the federal laws and funding that have improved the lives of people with disabilities during the past decades. The information in *Massachusetts Billions* has inspired a series of front page articles in the Boston Globe and is being used in grassroots campaigns to undo the terrible damage the new welfare law will do to Massachusetts residents with disabilities.

ARC Massachusetts: ARC Massachusetts played a key role in the successful budget "Campaign for 23,856 persons with mental retardation" which resulted in over \$20 million in new funding for services including raises for staff in the field, older unserved, family support and turning 22. This organization worked hard on forestalling changes in major federal programs such as Medicaid, IDEA, and Social Security. ARC Massachusetts received over 2,000 calls for information or resources, and sponsored trainings in inclusion, fair housing and estate planning. They continue to keep people updated on issues through the Advocate newsletter and a government update. ARC Massachusetts also kicked off the Family to Family Project, which is geared toward eliminating the waiting list for mental retardation services. The MDDC is aiding this project, which also has major funding from the Joseph P. Kennedy, Jr. Foundation, by supporting outreach to multicultural groups.

Personal Assistance Services Coalition (PAS): The Statewide Personal Assistance Coalition is an ad hoc group which has been working over the past several years to advocate for Personal Care Attendant services. The group is comprised of over 20 active members from across the state, including PCA service users, vendors and advocates. Over the past year, the Coalition has been involved in a number of efforts to protect and strengthen PCA services. When the Division of Medical Assistance issued a request for information just prior to New Year's Day, 1996, the Coalition organized a statewide response. Their proposal would have asked consumers to relinquish control to a centralized agency responsible for hiring and payment of PCAs. The response, made individually and in concert, clearly defended the central philosophy of consumer control in independent living. In the spring, the Coalition successfully advocated in the legislature for budget language aimed at protecting consumer control by requiring the inclusion of the disability community in the process of redesigning the PCA program.

Members of the Coalition have been meeting with DMA staff since March in an attempt to address two distinct issues: 1) changes in the way PCA applications are processed and 2) PCA employment liability. While these issues have not been resolved, they are receiving attention from the commissioner of DMA, as well as from officials at EOHHS. In the meantime, the Coalition has been instrumental in the drafting and filing of legislation which addresses these two issues. It is designed as a fallback, should there be no process through administrative channels. While sweeping and potentially costly in nature, the legislation already enjoys the support of 35 co-sponsors representing both political parties. There is recognition among legislators that the status quo cannot continue. This recognition is, in part, the fruit of several years of active education and advocacy by the PAS Coalition.

Health Care for All: Health Care For All is an organization dedicated to making health care accessible to everyone, regardless of income, social or economic status. They are particularly concerned about the most vulnerable members of society --- the uninsured, low-income elderly, children, people with disabilities and newcomers to the country. Their work combines policy analysis, information referral, personal and legal advocacy, community organizing and public education. Health Care for All spearheaded the coalition responsible for passage of the Health Care Access Bill.

V-F. REPORTING YEAR OTHER ACTIONS IN STATE

Uninsured: Health Care for All successfully fought: to expand the Children's Medical Security Plan for uninsured children; for a 1996 bill expanding health care for nearly 300,000 children, elderly, disabled and low income residents; to create the CommonHealth program for children and working adults with disabilities; and filed a class action lawsuit to make insurers share, with their subscribers, discounts they receive from providers. Ongoing work at Health Care For All includes ensuring the full implementation of Chapter 203; support for improving the operation of the Free Care Pool; and active organizing in communities hardest hit by federal changes in benefits. In addition, Health Care For All has worked towards protecting the public interest when non-profit institutions seek to convert to for-profit status. However, regardless of the incremental success achieved this year, access to health care could be further undermined by the proposed changes in Medicare and Medicaid.

Uncompensated Care Pool: Through the Massachusetts Uncompensated Care Pool (Free Care Pool), the state pays hospitals for treating uninsured patients. These people generally cannot get health insurance at work but are not poor enough to qualify for Medicaid. The Free Care Pool allows for immediate medical attention, such as visits to the emergency room. The Pool has been a safety net for hundreds of thousands of uninsured and underinsured Massachusetts residents.

The pool was originally funded by surcharges to health insurance bills. However, in the age of aggressive bargaining by a variety of health providers, hospitals have been forced to accept more of the financial burden. A Commission, created by Chapter 203 and comprised of representatives from hospitals, community health centers, consumers, businesses, insurers, the legislature and the administration, is examining the issue and proposing legislative changes to address the increasing demand for access to health care.

According to Health Care For All, since 1989, the number of uninsured residents in Massachusetts has doubled to nearly 800,000 residents, 150,000 of whom are children. Chapter 203 helped ensure that every child in Massachusetts has access to some type of health program whether it be through a parent's employer, state or federal program. In addition, another 60,000 seniors would receive some assistance with their prescription drug costs.

New England Waiver- Senior Initiative: The New England States plan to apply to HCFA for a Medicaid waiver to try a regional approach to administer subsidized health care for New England's elderly poor. Health care officials from six New England states have met with federal Medicaid administrators to find options for using millions of dollars spent on persons dually eligible for both Medicaid and Medicare. The proposal would allow the states to combine these funds. Presently older persons on both programs do not have coordinated care. The other New England states included people with disabilities, however Massachusetts did not in the initial plan. Massachusetts sees differences in the two populations and Medicaid officials have said they want to address them sequentially. The five year application would be submitted in the beginning of 1997 with a one year process for review and approval. Massachusetts would seek to include individuals with disabilities in the fourth year.

First, we want to acknowledge the thousands of dollars of volunteer time that are donated to carry out Council supported activities each year.

Many resources are created or continued as permanent components of the service delivery system due to the Council's previous advocacy efforts. An example of such an effort is the PASS Works Project, which was funded by the Council in past years. The writing of PASS Plans on behalf of consumers with disabilities through this project has generated approximately \$1,265,000. Council funding for this project ended in 1995, but funding is still being leveraged with a multiplier effect. The Department of Mental Retardation continues to provide resources to the project for continued trainings. The Office of Employment Services of Massachusetts Rehabilitation Commission provides on-going PASS Plan training and writing as part of a federally funded Systems Change grant. Council staff is a member of the Employment Services Action Council which is the oversight advisory body of this program. Other examples of the multiplier effect from previous activities include the Turning 22 Program and the State-Wide Head Injury Program.

Legislative advocacy activities resulted in new and continued funding for many programs serving people with developmental disabilities. Because the Council has worked hard to develop and support a strong advocacy network, it is impossible to identify to what extent Council activities alone contributed to these gains. However, along with the combined advocacy efforts of many consumers and advocates, over \$24,600,000 in increased funding occurred in the state budget for individuals with disabilities including:

- \$14 million allocated for a 4 percent cost of living increase for direct care providers earning under \$20,000 per year;
- \$200,00 allocated for additional interpreters at the Massachusetts Commission for the Deaf and Hard of Hearing;
- \$2 million allocated for family supports at the Department of Mental Retardation;
- \$2 million allocated for older unserved individuals with mental retardation who are living with elderly parents;
- \$400,000 allocated for persons who are turning 22 and are Deaf and Blind;
- \$5 million allocated for a pilot project between the Departments of Mental Retardation and Education to allow students currently in private schools funded through Chapter 766 to voluntarily return to a home setting with supports;
- \$1 million allocated for Child and Adolescent Services, the first increase in years.

In addition, passage of the Health Care Access Bill provides over \$70 Million for children's health coverage and an additional \$30 Million for prescription drugs for children. It is important to note that millions of direct service dollars would have been lost as a result of the reorganization plan submitted by the Governor in House One. Although the proposal identified these dollars as savings resulting from administrative efficiencies, the numbers suggest that in fact every agency impacted by the changes would have had less direct service dollars in fiscal 1997 than they did in fiscal 1996. Due to the advocacy efforts of the many organizations described in this report, these dollars were not lost.

Leveraged funds from MDDC grants amounted to over \$165,000 in direct match from grantees.

APPENDIX B**Report Dissemination Plan**

Dissemination of this annual report will be accomplished through direct mailings as well as notices that it is available upon request and in alternative formats. The Council will disseminate this annual report to the Governor, Massachusetts' Congressional delegation, the Massachusetts State Legislature, all Council members, all D.D. Act funded programs, and the Commissioners of key state agencies. In addition we will directly notify all organizations on our advocacy groups mailing list (450+) that the report is available upon request.

These efforts will ensure that all interested in Council activities will have the opportunity to request a copy of this report.

APPENDIX C**Massachusetts Developmental Disabilities Council --- MEMBERS****December 1996**

		Appointment <u>Date</u>	Term <u>Expires</u>
Jane Ambash		02/25/95	10/18/97
Patricia Bouchard		02/22/95	10/18/97
Barbara Chandler	<i>Exec. Off. of Elder Affairs</i>	02/15/96	02/15/97
Lucie Chansky		02/22/95	10/18/98
* John Chappell	<i>Mass. Rehabilitation Comm.</i>	04/25/96	04/25/97
Sheryl Cole		Reappointment pending	
Dennis Craig		12/29/94	10/18/97
Michael Dorsey		Reappointment pending	
Sherry Dottin		Reappointment pending	
Grayson Emery		06/23/95	10/18/98
* Mary Beth Fafard	<i>Department of Education</i>	02/21/96	02/21/97
Florence Finkel		12/27/94	10/18/97
Patricia Freedman	<i>Disability Law Center (P&A)</i>	05/01/95	10/18/97
Francis Galligan		05/01/95	10/18/97
Alan Gentle		02/22/95	10/18/97
James Gleason	<i>Shriver Center (UAP)</i>	05/01/95	10/18/97
Barbara Gopen	<i>Vice-Chairperson</i>	06/24/92	..
* Lorraine Greiff	<i>Office on Disability</i>	02/01/96	02/01/97
Yoang Hoon Jung		02/22/95	10/18/97
William Kiernan	<i>Institute for Comm. Inclusion</i>	02/22/95	10/18/97
Rosemary Larking		Reappointment pending	
Richard Merson		02/22/95	10/18/97
Sandra Milyko		02/22/95	10/18/97
Joni Mullane		02/23/95	10/18/97
Rogera Robinson	<i>Secretary</i>	02/23/95	10/18/97
Ruth Ann Rasbold		Reappointment pending	
* June Rowe	<i>Dept. of Mental Retardation</i>	05/01/96	05/01/97
Edith Schneider		04/07/95	10/18/97
Gerald Scott		Reappointment pending	
Craig Smith		Reappointment pending	
Ruth Smith		02/22/95	10/18/97
Robert Sneirson		02/22/95	10/18/97
Maureen Sullivan	<i>(Resigned 7/29/96)</i>	12/29/94	10/18/97
* Walter Sullivan	<i>Dept. of Attorney General</i>	04/23/96	04/23/97
Howard Wayne	<i>Chairperson</i>	11/05/93	..
Suzanne Welch		02/25/95	10/18/97
* Betsy Anne Youngholm	<i>Division of Medical Assistance(Medicaid)</i>	02/15/96	02/15/97

* STATE AGENCY REPRESENTATIVES.

** THE CHAIR AND VICE-CHAIR SERVE CONCURRENT WITH THE GOVERNOR.

MASSACHUSETTS DD PROGRAM STAFF

Council

Daniel Shannon, Executive Director
Deirdre Whelan, Esq., Legal Counsel
Peggy Freedman, Planner
Wayne Perry, Planner
Essie Orr, Admin. Assistant
Regina Brith, Special Projects Coordinator

Administering Agency

Liz Fancher, Program Coordinator
Craig Hall, Fiscal Coordinator
Harold Lieberman, Admin. Secretary

